

How can involving women with HIV strengthen the evidence base of our policies and programmes?

A methodology analysis

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Young women in Nepal © E. Tremlett

Background

- * Few examples exist of studies of treatment access issues for women living with HIV, outside the peri-natal context.
- * Even fewer examples exist of peer-led and -governed analyses of treatment access where women living with HIV are placed at the centre of design and implementation.
- * A multi-phase global review, to explore barriers and enablers to women accessing HIV care and treatment, was needed to address these gaps.
- * This unique and under-used methodology ensures experiences, realities, needs and priorities of women living with HIV in relation to treatment access *throughout their lives* are better understood, and creates a robust model for meaningful involvement.

Methods

- * The study (literature review, global consultation and country case studies) was informed by a Global Reference Group (GRG) of 14 women living with HIV from 11 countries.
- * The global consultation – designed and guided by the GRG – included women from key populations, different age-groups and countries worldwide.
- * GRG members conducted a pre-consultation with small groups of women living with HIV (see Figure 1), utilizing a ‘holistic well-being’ approach to define key themes, informing focus group discussion (FGD) and interview guides.
- * The GRG coordinator established a closed international email listserv for 19 women living with HIV and moderated an extensive e-discussion exploring treatment access issues.
- * The GRG then contributed to a literature review, led the global consultation (pre-consultation, e-discussion, FGDs and one-to-one interviews) and provided guidance for country case studies informed by GRG members.
- * Each review phase was built and informed by preceding phase(s) (see Figure 2).

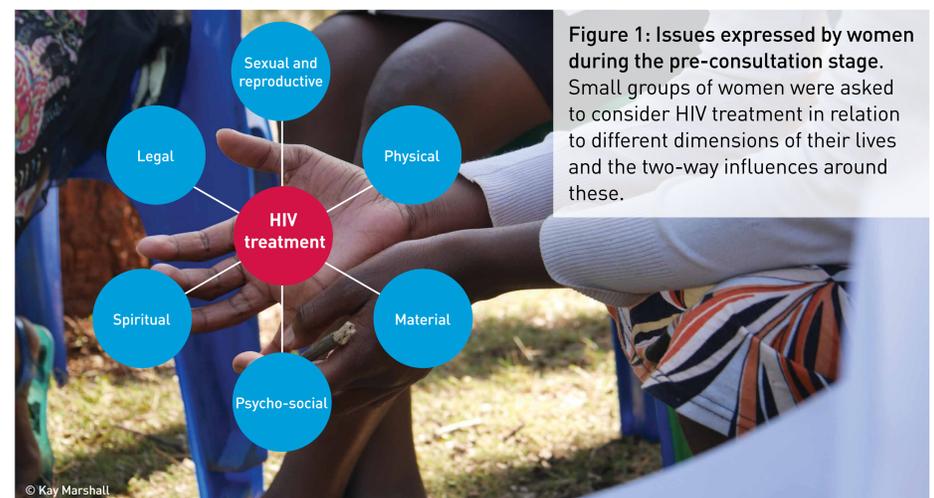


Figure 1: Issues expressed by women during the pre-consultation stage. Small groups of women were asked to consider HIV treatment in relation to different dimensions of their lives and the two-way influences around these.

“It is always good to share experiences and know we aren’t alone. It has been a really valuable experience and I have learnt so much.”
YOUNG WOMAN, NEPAL

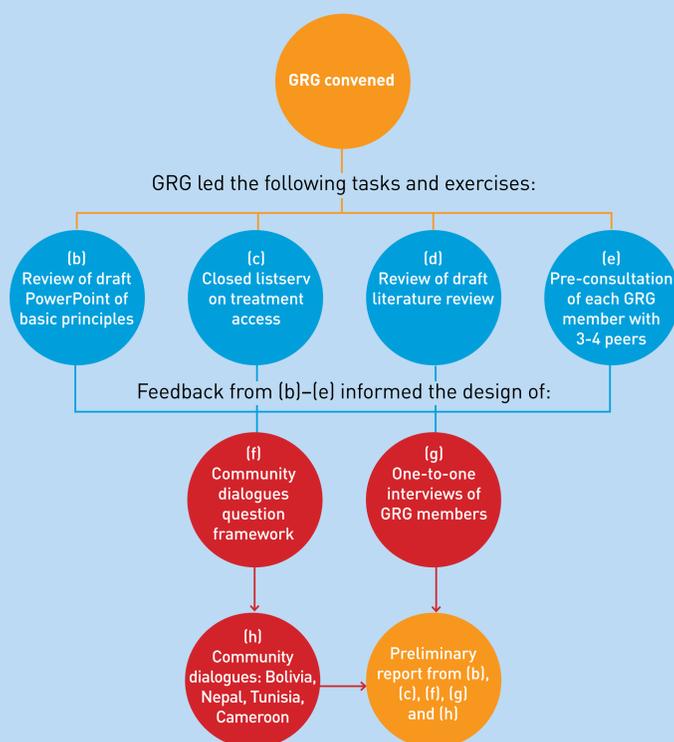
Results

- * The methodology used an interactive ‘community dialogue’ questionnaire framework that expanded traditional FGD formats, through involvement of women living with HIV in formulating questions, facilitating discussions and analysing results.
- * The community dialogue framework, developed through leadership of women living with HIV, included specific women’s rights-related dimensions to care and treatment access, and the administration of the questionnaire framework by women living with HIV created trust and support among participants for in-depth, rich qualitative findings.
- * Local ethical review processes for community-based research were developed through the GRG governance structure.
- * Participants noted improved self-esteem, empowerment and understanding of treatment barriers from their experiences as part of the GRG, focus group leaders and interviewers.
- * 175 women living with HIV participated in peer-led FGDs and interviews in Tunisia, Bolivia, Nepal and Cameroon.
- * In all, the 203 women living with HIV, from 17 countries globally, appreciated this holistic focus on women’s health and rights, compared with traditional questions.

“At the end of every discussion everyone felt very happy to share their experiences ... and know the facts ... they want that the next generation should not face the same problems that they are facing now: ‘We hope, and our expectation is, for not only a change but a huge revolution in the place where we belong’.”
GRG MEMBER, NEPAL

“All interviewees commented on how rewarding it was to have a chance to analyse their own experiences in relation to a broader context, and how few opportunities there were to do this.”
GRG COORDINATOR

Figure 2: Global consultation process



Conclusions/lessons learnt

- * Meaningful involvement of women living with HIV (as intended beneficiaries) in implementation science – assessing service delivery – creates enhanced and contextually-specific evidence to inform treatment uptake and utilization.
- * The GRG model presents a framework for involving women living with HIV that emphasizes the critical contributions of women’s agency, quality of care, rights and choice.